Using information prescriptions to refer patients with metabolic

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Objectives: The objectives of this study were to assess the reactions of adult patients and parents of children with metabolic conditions to receipt of an ''information prescription'' (IP) to visit Genetics Home Reference (GHR), a National Institutes of Health/National Library of Medicine online resource, and evaluate the perceived utility of information found on the site.

Methods: Patients seen at the University of Utah Metabolic Service Clinic were invited to participate in the study and asked to complete an initial survey to gather demographic data and an online survey six weeks later to obtain information about user experience.

Results: Fifty-three of 82 individuals completed both surveys, for an overall response rate of 64.6%. Most respondents (88.7%) agreed that receiving the IP was a ''good idea,'' and nearly all used the IP to visit GHR. More than three-quarters (79.6%) agreed that information on GHR supplemented a physician's advice; 60.4% reported an improved understanding of a health condition; and 41.5% either looked for or would consider looking for additional information. Eighty-six percent of respondents were satisfied with the information found on GHR, and 80% would recommend the site.

Conclusions: Use of an IP to direct patients to GHR was well received, and retrieved information was perceived as useful in key areas. The high level of satisfaction with GHR argues for expanded use of the IP approach in this patient population.

INTRODUCTION

Consumers are seeking health information online in record numbers [1]. However, the quality of health information found on the Internet is variable, and patients sometimes desire help from physicians to find reliable websites [2–4]. An ''information prescription'' (IP) provides specific, evidence-based information to patients to help them manage health conditions [5]. Physicians may use IPs to direct patients to trustworthy websites to retrieve condition-specific information [6], sometimes writing the patient's medical condition on a pad similar to those used to prescribe medications [7]. Feedback from both providers and patients has been encouraging: Some physicians suggest IPs help explain difficult concepts to patients [7], and patients report the information helps them make better health decisions [8].

The parents of children referred for a possible genetic diagnosis can benefit from professional guidance to access additional health information and psychological support [9]. Parents may be more likely to seek information online about their children's medical conditions when this approach is suggested by a health professional [10]. According to Taylor, Alman, and Manchester, 92% of survey respondents (the majority of whom were parents or guardians) visiting general genetics clinics said they would be likely to visit a website that was recommended by a geneticist [11]. While previous studies report positive outcomes with use of IPs in pediatric and adult patient populations [5, 7, 8], to the authors' knowledge, this approach has not been evaluated among

Highlights

- Use of an information prescription (IP) to direct patients to Genetics Home Reference (GHR) was well received in this study of patients with metabolic conditions.
- Information retrieved from GHR was perceived as useful in key areas, including enhancing user understanding of medical conditions and encouraging additional information seeking.
- Users reported a high level of satisfaction with GHR and would recommend the site to others.

Implications

- The IP approach used in this study may be implemented in other practice settings.
- Patients will access online genetic health information when directed by a trusted provider to a reliable resource such as GHR.
- Referral to GHR supplements information communicated by health care providers during clinic visits.

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Supplemental Appendixes A and B and supplemental Figures 1 and 2 are available with the online version of this journal.

adult patients and parents of children with metabolic conditions, a class of genetic diseases involving disorders of metabolism.

The Genetics Home Reference (GHR) website <http://www.ghr.nlm.nih.gov> was developed by the National Library of Medicine (NLM) to provide consumers and providers with easy-to-understand, accurate, and reliable health information about genetic conditions [12]. The website provides information about more than 550 health conditions, diseases, and syndromes. The objectives of this prospective study were to assess the reaction of adult patients and parents of children with metabolic conditions to a physician-directed IP to visit GHR and the perceived utility of the information that study participants found on the site. Key outcome measures included: respondents' health information–seeking and –sharing behaviors, use of computers and the Internet, prior use of GHR, reaction to and use of the IP, user experience with GHR, planned use of information found on GHR, assessment of the quality and trustworthiness of GHR, satisfaction with GHR and predictors of satisfaction, future use, and recommendation of GHR to others.

METHODS

The study was approved by the University of Utah Institutional Review Board.

Survey development

Two survey instruments were created to collect outcome data. The surveys were derived from an instrument previously developed by the American College of Physicians Foundation and NLM and used to evaluate NLM's Information Rx (Prescription) Program [7, 8]. Both surveys were pretested and revised based on feedback from a convenience sample of parents and caregivers of children with special health care needs. The persons who participated in the pretest received services from the Division of Community and Family Health Services at the Utah Department of Health.

The two survey instruments were administered in a pre-post fashion where the intervention was the IP (Figure 1, online only) and subsequent visit to GHR. A twenty-eight-item paper survey (Appendix A, online only) was administered during a patient or caregiver's initial clinic visit. This instrument sought to characterize patient or caregiver behaviors regarding searching for and using health information retrieved online, as well as more broadly assess Internet use. Demographic information was collected to contact participating patients and caregivers to remind them to complete the second survey. A second thirty-one-item online survey (Appendix B, online only) was hosted on a secure website managed by NLM. The second instrument was completed after patients and caregivers received an IP to visit GHR, and it focused on user experiences and perceived utility of the health information found on GHR.

Description of the Genetics Home Reference (GHR) website

The GHR website provides links to information about genetic conditions, genes, and chromosomes, as well as links to concepts and tools for understanding human genetics (handbook, glossary, and resources). For example, the illustrated *Help Me Understand Genetics Handbook* provides information about patterns of inheritance, types of gene mutations, and genetic testing. GHR's Resource page provides links to other reliable online genetic resources. Additional links to information about newborn screening issues and other topics are available (Figure 2, online only).

Study enrollment

A convenience sample of adult patients (age eighteen or older) and parents or guardians of newborns or children with metabolic conditions who received medical care at the University of Utah Metabolic Service Clinic between April 28 and November 3, 2008, were invited to participate. This study focused on the metabolic conditions diagnosed or confirmed by the medical director and/or colleagues at the University of Utah Metabolic Service Clinic and detected by newborn screening. The study did not enroll adult patients and caregivers of children with hearing abnormalities, hemoglobinopathies, and endocrine disorders, who are diagnosed and treated by different providers at other Utah clinics.

Study enrollment criteria included referral by the clinic's medical director, a willingness to participate, and English language skills. All patients with a confirmed diagnosis of a metabolic condition were eligible for referral into the study, with the exception of children who were ill and needed urgent care or whose visits were scheduled at times when the first author was unavailable to recruit. Participants were given a paper IP containing the uniform resource locator (URL) for GHR, a brochure describing GHR (''Your Guide to Understanding Genetic Conditions'') [13], a list of Utah public libraries to ensure Internet access during the study period, and a study description. The medical director or a colleague wrote the name of the patient's medical condition on the IP in an effort to facilitate health information retrieval. The medical director or colleague also signed and dated the IP.

After obtaining informed consent, participants completed the first survey. One or both parents were eligible to enroll. All participants were instructed to visit GHR at least once during the six weeks following the clinic visit. Three weeks after the clinic visit, participants received email and letter reminders encouraging them to visit GHR. At six weeks, participants received a second round of email and letter reminders containing the URL, user name, and password needed to access the second, online survey. Up to three follow-up attempts (by email and telephone) were made to contact participants who did not complete the second survey at the end of the

Table 1
Comparison of demographic characteristics of persons who completed both surveys (n=53) and persons who completed only the initial survey (n=29)

Characteristic		Completed both surveys (n=53)		Completed initial survey (n=29)		*P* value
		n	(%)	n	(%)	
Role	Parent, guardian, or caretaker	50	(94.3%)	29	(100.0%)	0.549
	Adult patient	3	(5.7%)	0	—	
Gender	Male	14	(26.4%)	9	(31.0%)	0.798
	Female	39	(73.6%)	20	(69.0%)	
Age in years	Range	20–46		21–56		
	Median	33		27		0.006†
Race/ethnicity	White, not of Hispanic origin	49	(92.5%)	26	(89.7%)	0.694
	Other	4[a]	(7.5%)	3[b]	(10.3%)	
Highest level of education	Less than high school	0	—	1	(3.4%)	0.030‡
	High school graduate or equivalent	2	(3.8%)	5	(17.2%)	
	Some college or vocational school	21	(39.6%)	14	(48.3%)	
	College graduate	13	(24.5%)	7	(24.1%)	
	Some postgraduate school	2	(3.8%)	0	—	
	Graduate or professional degree	15	(28.3%)	2	(6.9%)	
State of residence	Utah	47	(88.7%)	27	(93.1%)	0.706
	Other	6	(11.3%)	2	(6.9%)	
Patient diagnosis	PKU*	28	(52.8%)	12	(41.4%)	0.385
	MCAD§	8	(15.1%)	8	(27.6%)	
	Other	17	(32.1%)	9	(31.0%)	

† $P<0.05$, Wilcoxon test.
‡ $P<0.05$, Fisher's exact test.
Note: 53 of 82 study participants (64.6%) completed the online survey; percentages may not add to 100 due to rounding.
Note: The category "Other[a]" includes Hispanic, Asian, "White and Hispanic," and "Mixed (White/Asian)"; the category "Other[b]" includes American Indian/Alaskan Native and Hispanic.
* PKU or phenylketonuria.
§ MCAD or medium-chain acyl-CoA dehydrogenase deficiency.

six-week period. In an effort to optimize the survey response rate, an additional reminder letter (along with a memo signed by the clinic's medical director) was mailed in December 2008 or early January 2009 to all study participants who had not yet submitted an online survey. The data collection phase of the study ended on January 15, 2009.

Data management

Individual responses to the two surveys were linked by a unique four-digit ID number. An ID number was assigned to each participant at the time of enrollment and subsequently provided to participants in the six-week reminder email and letter. Participants were instructed to enter their ID number in the designated field of the online survey. Online survey data collection was overseen by GHR's staff.

Statistical analysis

Univariate analysis was conducted using the Wilcoxon test and Fisher's exact test as appropriate to compare characteristics of two groups: persons who completed both surveys and those who completed only the first survey. Correlation analyses were conducted using the Spearman rank correlation with Bonferroni adjustment. All statistical analyses were conducted with R, version 2.09 [14].

RESULTS

Of the 327 patients scheduled to receive medical care during the study enrollment period, 14 were listed in the clinic log as speaking a language other than English. One of these patients—who spoke both Spanish and English—was approached but declined to participate. Therefore, an estimated 13 of 327 or 4.0% of the potentially eligible patients were excluded from participation due to lack of English language skills. Eighty-eight patients and parents or caregivers were ultimately approached to participate in the study; 6 refused. Eighty-two persons completed the first survey. Fifty-three persons (representing 49 discrete families) completed both the first and second surveys, for an overall response rate of 64.6%. Of these, 50 were parents or guardians of children with metabolic conditions and 3 were adult patients. The median length of time from completion of the initial survey to submission of the online survey was 52 days.

A comparison of the demographic characteristics of the persons who completed both surveys (n=53) and those who completed only the initial survey (n=29) is provided in Table 1. Persons who completed both surveys were significantly older (Wilcoxon test, $P=0.006$) and more highly educated (Fisher's exact test, $P=0.030$). Phenylketonuria (PKU), an autosomal recessive genetic disorder characterized by a deficiency of the liver enzyme phenylalanine hydroxylase needed to metabolize the amino acid phenylalanine to tyrosine, was the most common patient diagnosis among both groups. Neither number of years since diagnosis nor number of hours spent using the Internet was significantly associated with completion of the second, online survey (data not shown). The following results are based on the responses of the 53 persons who submitted both surveys (referred to as respondents from this point forward). Not every respondent answered all survey questions.

Health information–seeking and–sharing behaviors

Twenty-five respondents (47.2%) reported looking up sources of medical information either ''very'' (15.1%) or ''somewhat'' (32.1%) frequently. Three-quarters of the respondents reported that it was ''very'' (39.6%) or ''somewhat'' (35.8%) easy to read health information on a computer, compared to a book or pamphlet. About half of respondents (49.0%) indicated that they discuss the medical information that they look up with their doctors either ''very'' (13.2%) or ''somewhat'' (35.8%) frequently. Approximately 85.0% reported that it was ''very'' (39.6%) or ''somewhat'' (45.3%) easy to understand the medical issues that their doctors discuss with them.

Use of computers and the Internet

All respondents reported having a computer either at home (92.5%) or at both home and office (7.5%), with the majority of respondents (52.8%) checking email and using the Internet up to 1 hour a day. Seventeen respondents (32.1%) reported checking email and using the Internet an average of 2 to 4 hours a day, with 7 respondents (13.2%) reporting an average daily use of more than 6 hours.

Prior use of GHR

Nearly all of the respondents (96.2%) reported never visiting GHR prior to receiving the IP at the clinic.

Reaction to and use of the information prescription

Thirty-one respondents (58.5%) strongly agreed with the statement, ''I think receiving a prescription from my doctor to visit the Genetics Home Reference website for more information is a good idea.'' Sixteen respondents (30.2%) somewhat agreed; 6 respondents (11.3%) neither agreed nor disagreed with this statement; and none disagreed.

The majority of respondents (84.9%) felt that they had received enough information at the clinic visit to feel comfortable using GHR, and all but 3 used the IP. (Two survey respondents reported that they did not visit GHR for the following multiple reasons: difficulty understanding written health information, preference for another Internet source of health information, adequate knowledge of their child's medical issues, belief that what they were told by their child's doctor was sufficient, and lack of time. A third respondent reported a visit to GHR prior to study enrollment.) Among the 50 respondents who ''filled'' the IP, 24.0% reported visiting the site once, 52.0% reported visiting the site twice, and 24.0% reported visiting the site 3 to 5 times. Enrolled participants who might have used the IP to visit GHR but who did not ultimately submit a survey could not be tracked.

Twenty-two of the 53 respondents (41.5%) submitted an online survey after receiving the 3- and 6-week reminder emails and letters that all enrolled participants received. Ten of 53 (18.9%) respondents required 1 follow-up email reminding them to visit GHR and submit an online survey. Twenty of 53 (37.7%) respondents required 2 follow-up emails. Eleven of these 20 also received a reminder letter and memo signed by the clinic's medical director and, in 7 cases, a reminder telephone call (along with an accompanying email to resend the survey link in 4 cases). Due to enrollment in late December 2008, 1 individual received 1 follow-up email and the reminder letter and memo signed by the clinic's medical director.

User experience with GHR

Seventy-six percent of respondents reported that it was either ''very'' (46.0%) or ''somewhat'' (30.0%) easy to find the information they were seeking in GHR. The majority of respondents also reported that the information in GHR was either ''very'' (47.1%) or ''somewhat'' (39.2%) easy to understand and that the information relating to their own or their child's medical condition was either ''very'' (43.1%) or ''somewhat'' (41.2%) helpful. Five respondents (10.0%) noted missing information related to their child's condition. For example, parents reported not being able to locate information about hyperphenylalaninemia (a mild form of PKU) or ways to troubleshoot common health problems experienced by children with specific disorders. Respondents reported visiting other websites (webMD.com, MedlinePlus.gov, and the Ask the Geneticist website) to attempt to locate missing information.

Planned use of information found on GHR

Respondents were asked how they used or planned to use the health information found on GHR. Almost one-third (30.2%) of respondents reported that they had discussed or were planning to discuss the health information they found with their or their children's physicians, and about half (49.1%) had discussed the information or were planning to discuss it with family or friends. A majority of respondents (60.4%) reported an improved understanding of an illness or health condition, and 28.3% reported that information found on GHR influenced or might influence future health decisions for themselves or their children. Furthermore, 41.5% of respondents looked for or would consider seeking additional health information, and 11.3% either contacted or planned to contact a local support group.

Assessment of the quality and trustworthiness of GHR

Respondents were also asked to rate their level of agreement with 4 statements related to GHR (Table 2). Of note, 96% of respondents reported they trusted the information on GHR because it was prescribed by their doctors.

Satisfaction with GHR

Overall, 86% of respondents reported being either ''very'' (58%) or ''somewhat'' (28%) satisfied with the

Table 2
Respondent level of agreement with specific statements about Genetics Home Reference (GHR)

Statement	Strongly agree		Somewhat agree		Neither agree nor disagree		Somewhat disagree		Strongly disagree
	n	(%)	n	(%)	n	(%)	n	(%)	n
I trust the information on the GHR website because my or my child's doctor prescribed it.	31/50	(62.0%)	17/50	(34.0%)	2/50	(4.0%)	0/50	—	0/50
A high-quality source of health information helps me talk to my or my child's doctor.	33/50	(66.0%)	14/50	(28.0%)	3/50	(6.0%)	0/50	—	0/50
The health information that I find on the GHR website will help me make better health decisions for myself or my child.	21/50	(42.0%)	20/50	(40.0%)	8/50	(16.0%)	1/50	(2.0%)	0/50
The information I received on the GHR website added to what doctors told me about my or my child's condition.	22/49	(44.9%)	17/49	(34.7%)	9/49	(18.4%)	1/49	(2.0%)	0/49

health information they found on GHR. A sample of user comments is provided in Table 3.

Predictors of satisfaction with, future use of, and recommendation of GHR to others

Seventy-eight percent of respondents indicated that they were either ''very likely'' (38%) or ''likely'' (40%) to use GHR again. When compared to all other health information sources currently used by the respondents (whether or not these were located on the Internet), 44% of respondents indicated that they would use the GHR website in the future either ''very frequently'' (8%) or ''frequently'' (36%). Eighty percent of respondents indicated that they were likely to recommend the site to others. Only 3 individuals (6%) reported they were ''unlikely'' or ''very unlikely'' to do so.

Gender, daily hours of Internet use, time since diagnosis, and education level were examined to determine whether these characteristics influenced survey responses, but none was significantly correlated with other survey variables. However, respondents who reported finding information more easily reported greater overall satisfaction with GHR ($r=0.63$, $P<0.01$). There was also a strong correlation between visiting pages about specific genetic conditions and how frequently the respondent planned to use the site (compared to all other health information sources currently used, whether or not located on the Internet) in the future ($r=0.63$, $P<0.01$), as well as a significant correlation between likelihood of future use and recommendation of GHR to others ($r=0.76$, $P<0.001$).

There were too few adult patients to allow for meaningful comparison with enrolled parents. However, all three adults ''strongly'' or ''somewhat'' agreed that receiving an IP to visit GHR was a good idea and were ''very'' or ''somewhat'' satisfied with the health information found on GHR.

DISCUSSION

The goals of the present study were to assess the reaction of adult patients and parents of children with metabolic conditions to receipt of an IP to visit GHR, a website providing genetic information for the general public, and the perceived utility of information found on the site. Participants in this study were enthusiastic about the IP; in fact, almost 89% of respondents agreed that receiving an IP was a good idea, and nearly all respondents used the IP to visit GHR. In addition, three-quarters of respondents reported visiting the site 2 or more times during the study period. While other studies have pointed to the successful implementation of IPs in adult [7] and pediatric patient [6] populations, the findings from this study indicate the IP also is well received by adult patients and parents of children with metabolic conditions.

In fact, 50 of the 82 initially enrolled participants used the IP to visit GHR, for an overall IP ''fill'' rate of nearly 61%. The rate observed in this study was slightly lower than the 65% rate reported in a study that also employed email prompts [6] but compared favorably to fill rates recorded in other studies of IP implementation, in which participants did not receive such prompts [5, 15]. The use of email reminders

Table 3
Sample user comments about GHR

- ''This website was very informative and easy to understand.''
- ''I work with families who have children with special needs. I plan to give this site information to those families that this applies to. I feel that it may help them understand their child's condition. Especially those who for whatever reason didn't get enough information from their child's physician.''
- ''The GHR website needs a personal touch.''
- ''I really think it is a great site and will help a lot of people. I only wish we would have had something like this when I was born so my parents could have read and talked to others who have experienced my condition.''
- ''The GHR website seems ideal for educating a parent who has just recently learned that his/her child has a genetic disorder. For someone like me who has been visiting with doctors and learning about my child's condition for well over two years now, the site didn't appear to provide any new or compelling information to motivate me to spend much time investigating it….I would like to see the GHR website offer the following: (1) More solutions and suggestions related to PKU management; (2) a problem solver using a decision-tree method for diagnosing common problems experienced by PKU children; (3) An Ask A Dietician (like the Ask the Geneticist service).''

clearly played a role in this study's response rate: Approximately 59% of respondents required at least 1 follow-up email prior to online survey submission. The results supported those of Ritterband et al., who found that email prompts improved compliance with web-based IPs [6]. Similar to that study, in which reminder emails contained the website's address, the follow-up emails sent to participants in the present study contained links to GHR and the online survey, facilitating access to both sites and likely enhancing compliance. Of note, the use of email as an adjunct to Internet-delivered interventions has been shown to also support behavior change [16].

Feedback from survey respondents indicated that the information found on GHR was useful in several ways. For example, 80% of survey respondents agreed that the health information they found on GHR added to what their physicians had told them, and almost all respondents agreed that use of a high-quality source of health information encouraged communication with providers. Sixty percent of respondents reported an improved understanding of their own or their children's medical conditions after visiting GHR, and 42% reported that the site prompted them to look for, or consider seeking, additional health information. These results were similar to those observed by Siegel et al., in which 70% of patients reported that information found on MedlinePlus improved their understanding of an illness or health condition and 36% said it influenced whether they would look for more health information [7].

Specific user comments were interesting and generally positive. Some suggestions for improving the site included providing more information about hyperphenylalaninemia and links to sites with practical advice regarding management of PKU. User comments were shared with GHR's developers for consideration as appropriate.

While several respondents said they had been living with their children's medical condition for some time and, as a result, did not find new information on GHR, 86% of users in the present study expressed satisfaction with the information they found on the site, and 80% would recommend it to others. The number of years since diagnosis was not significantly correlated with satisfaction, future use of GHR, or probability of recommending the site to others. Other studies have shown that duration of symptoms does not appear to influence patients' desire for links to medical websites and that cancer patients continue to seek information on the Internet post-treatment [2, 17].

Patient satisfaction with provider-referred websites has been noted by others. For example, in a study of physician-directed email IPs with links to MedlinePlus, two-thirds of patients reported satisfaction with the information found on the IP site and 86% said they would use the site again [15]. Furthermore, 93% of patients who were directed by their physicians to retrieve condition-specific health information on MedlinePlus reported they would use the IP site again, and 91% would recommend it to others [7]. Parents in a randomized controlled trial of IP use in a general pediatric clinic who used prescribed websites were significantly more likely than nonusers to state that they would use the IP again in the future and had already recommended the IP to family members or friends more often than nonusers during the follow-up period [5].

Persons who completed both surveys were significantly older and more highly educated than those who completed only the initial survey. Persons who did not complete both surveys might have perceived that they received adequate information from their physicians and, therefore, did not feel compelled to visit GHR. Another possibility might be that, although conceived as a consumer-friendly website, individuals with fewer years of formal education might have been less inclined to visit GHR, possibly anticipating that they would have difficulty understanding the genetic information on the site.

This study is unique in two key ways. First, while physician-directed IPs have been used in other patient populations, to the authors' knowledge, this approach has not previously been implemented among adult patients and caregivers of children with metabolic disorders. Second, while previous studies have employed physician-directed IPs to various websites, including NLM's MedlinePlus website, this study is the first to use an IP to direct patients to GHR, a website specifically designed by NLM for consumers seeking online genetic information.

The findings from this study might not be generalizable to other populations given the high level of education of the participants and the fact that all respondents had home computer access. In fact, Utah is among the most wired states in the country, with 74.8% of Utah residents able to access the Internet from home [18]. Furthermore, three-quarters of the study participants found it easy to read health information on a computer compared to books or pamphlets. Another limitation was the use of a convenience sample, which might have been a source of bias. Expansion of this study in a larger, more diverse population is needed to tease out any potential effects of education and Internet access on user experience with GHR. Potential next steps might include similar studies in other states or regions and/or implementation of the study intervention by physicians caring for patients with other genetic conditions. In any case, results from the present study can serve as baseline data for future studies of GHR, and study outcomes may be adapted to evaluate user perception of other websites.

Increasingly, parents are using the Internet to retrieve health information for their children and desire professional guidance to locate information that is accurate and reliable [19, 20]. This study is important because it demonstrates that adult patients and parents of children with metabolic conditions will visit a previously unknown website to retrieve health information when directed by a trusted health care provider. The high level of satisfaction with GHR argues for expanded use of the IP approach in this patient population.

CONCLUSIONS

Use of an IP to direct adult patients and parents of children with metabolic conditions to GHR was well received by study participants in a medical clinic setting. Email reminders enhanced compliance with online survey submission. Retrieved information was perceived as useful in several key areas. Respondents expressed a high level of user satisfaction with GHR. Referral to GHR may enhance medical management by providing accurate and reliable health information to patients with metabolic conditions, encouraging communication with providers, and prompting further information-seeking behaviors. Potential areas of improvement to GHR include expansion of resource links regarding management of PKU.

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